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ABSTRACT

This theme issue addresses special concerns of single parents of children with disabilities. Parents are encouraged to give themselves time to heal, to feel their feelings, and to find a support group. Developing a positive attitude is also encouraged through pointing out some advantages to the single parent role and suggestions on becoming a positive role model and discovering oneself. Guidelines for developing a support system including the ex-spouse, other relatives, other special parents, other singles, and housemates are offered. Guidelines specifically for the working single parent address choosing child care and finding the right kind of work (including creative options such as flexible working hours, job sharing, and part-time work). Then, practical do's and don'ts are offered such as: "do find time for yourself"; "don't hide or isolate yourself"; "do keep your home life stable"; and "don't neglect your health." Finally, a psychologist, George Popper, briefly discusses divorce and the parents of a special child. (DB)

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Special Parent ★Special Child

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THE SINGLE PARENT

Being a single parent requires courage, an unflagging spirit and above all the determination that you can and will endure. However, when the child you are left to rear has a handicap the role of single parenthood can become overwhelming. The picture needn't be so grim if you develop a support system and effective ways to cope.

In this issue we will focus on the challenges faced by the single parent of a special child and how to create a lifestyle that encourages growth, stability and effective functioning for everyone in the family.

Ways to cope

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Although it may seem that life has dealt you a cruel blow, there are ways to develop the attitudes necessary to surmount the difficulties thrust upon you.

Give yourself time. As trite as this sounds, time *does* heal all wounds. The single parent needs time to adjust to the emotional trauma of the loss of a spouse, whether by death, separation or divorce. Expect to feel abandoned, scared, angry—even to the point of rage—and overwhelmed by runaway feelings and emotions. This is a natural course of events and,although hard to believe, your body actually needs this type of physical and psychological ventilation. Repressing your true feelings and assuming a "stiff upper lip" only masks inner turmoil. Very often these feelings are likely to surface later in the form of depression, anxiety, insomnia and physical illness.

Feel your feelings. In order to cope with your feelings you must first come to grips with them, even the extreme ones. Give yourself permission to feel the sorrow, the fear, the anger, the loneliness. It's OK to cry—tears are healing! Learn to express what's on your mind. It's helpful to find a friend to whom you can confide your innermost concerns and worries.

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Find a support group. Sometimes it's best to turn to those who are in similar circumstances. Those who have been there before have more understanding of what you are going through. There are groups for single parents, bereavement groups, divorce adjustment groups. Listings for these organizations can be found in local newspapers or you can contact your clergyman or mental health clinic. Community groups such as the YMCA, YWCA, YMHA or YWHA among others often sponsor such support services; look in your telephone yellow pages for listings.

Developing a positive attitude

The negative features of single parenthood are only too obvious—loneliness, anxiety over making major decisions, stress over financial hardships, worry about child care, guilt over the situation's effects on the children—and seem to compound when the child you raise singlehandedly is disabled.

If you look for them, you will find positive aspects to the single parent's role :

- The single parent can focus more undivided time on the child, increasing the potential for closeness and sharing.
- The tension from arguments over child rearing practices is absent in one-parent situations.
- If the marriage itself has been unhappy, its dissolution may produce a healthier atmosphere for the rest of the family.
- Children often rise to the occasion, becoming more independent and resilient in single parent households.
- The unexpected bonuses of honesty and openness in single parent families ultimately foster better parent and child relationships. When a single parent lacks the energy to mask his or her true feelings, children are better able to perceive things as they really are.

Become a positive role model. Children emulate the attitudes and behaviors they observe around them. If you are negative, bitter or find little worth in your life, your children will too. If you can believe that although life is a challenge, things will go on, your children will think so too.

Children feel safe and protected when their environment is consistent. Maintain as many household routines as possible, making sure chores are done, mealtimes are pleasant, the laundry is kept up. It's also important to foster an open atmosphere that invites family members to share their feelings with you.

ABOUT SPECIAL PARENT/SPECIAL CHILD:

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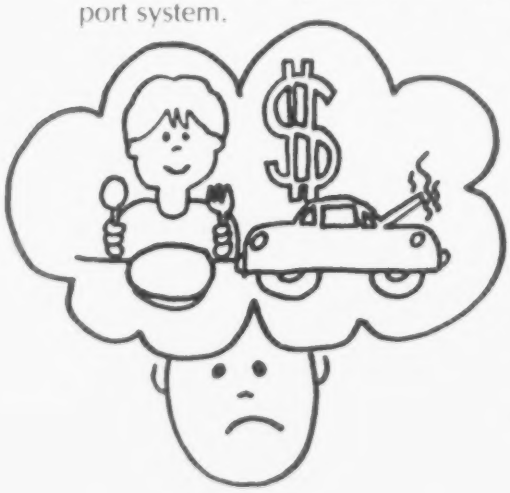
Self-discovery. When you find you are able to juggle the demands of being mother, father, disciplinarian and breadwinner all at once, the feeling of accomplishment often outweighs the negatives in your life. As one single parent commented, "I never fully understood the meaning of 'A man's reach should exceed his grasp' or 'What's a heaven for' until I realized I was living proof. As the single parent of a disabled child I discovered strengths in myself I didn't know existed. I've plumbed both depths and heights and I can honestly say I'm really proud of myself for having come through."

Developing a support system

All single parents face common problems; there are unique considerations, however, if the child you rear alone has special needs. Every single parent needs a support system but the single parent of a handicapped child cannot function without one. The extra time, care and supervision required by the special child can tax the single parent's reserves to the limit.

Finding help. It's best to be honest with yourself. It's unhealthy for everyone concerned to deny that you need help until you have reached the breaking point. Evaluate significant family members, friends or paid babysitters who can become part of your support system.



It's also important for your special child to become accustomed to being cared for by others. Doing this from the outset will enable you to go to work, develop new friendships and have a life of your own. Reliable, compassionate alternative care-givers can offer your child a rewarding experience. Here are some suggestions:

Besides making excellent babysitters, *parents and in-laws* can also become a source of emotional support and financial assistance. Don't overlook their offers to help. If none are forthcoming, don't be too embarrassed to ask. Many times parents and in-laws are eager to help but don't wish to overstep their bounds. It's up to you to let them know exactly how best to assist you.

Ex-spouse. Your ex-spouse has an obligation to take an active role in your child's welfare. Evenings, weekends and vacations can be shared on a scheduled basis providing you with free time and your child with the benefit of a relationship with the other parent.

Other relatives. Consider yourself fortunate if you have uncles, aunts or other trusted family members who are willing to help. It's

best to make sure that your relatives know your child's limitations and are given guidance on specific techniques necessary to care for your child.

Other special parents. Check into sharing or exchanging babysitting time or car pooling with other parents who have a handicapped child.

Other singles. Perhaps you can develop a barter system with single friends, even those who don't have any children. Offer to cook a meal or run an errand in exchange for child care services.

Housemates. Unique problems require unique solutions. Some creative single parents have teamed up with others in similar circumstances to share housing, related costs, child care responsibilities—consider the popularity of TV sitcoms such as "Kate and Allie" where two female heads of families live together with their respective offspring. Although not for everyone, it is an attractive alternative for a growing number of single parents.

The working single parent

Many single parents find themselves in reduced financial circumstances. Increases in the cost of living and running a household can drain the resources of the widowed single parent, and, in the case of divorce, these expenses are often too much for the single breadwinner. Juggling work and child care is the most onerous task facing the single parent. Choosing the right kind of child care or after school care is critical when the child has special needs. Here are several options:

- *Friends or relatives* can be paid for specific days or times they sit for you. Payment on a regular basis insures reliability and puts things on a professional footing.
- *Family day care* consists of leaving your child with a mother or caregiver who takes care of one or more children in her own home.
- A *full-time babysitter or housekeeper arrangement* in your own home is often the best and most convenient option. Expenses can be offset if you are able to offer room and board.
- *Day care* refers to all-day care, often up to 12 hours, and is held in a licensed center where teachers and assistants provide supervision, activities and meals.

Finding the right source of child care. If your child is of school age, your school social worker or guidance counselor may be a good resource for suggestions on after-school programs.

If full-day services are required, look in your telephone directory yellow pages for listings under "day care," "sitting services" or "nurseries." Contact United Way or your local Department of Human Resources of Department of Mental Health for listings. Local colleges or universities with special education departments may have college students able to provide care in your own home.

Organizations such as the Association of Retarded Citizens (ARC) or United Cerebral Palsy or Easter Seals may also be able to make suggestions.

Always evaluate any child care organization or babysitter carefully before entrusting your child to them. Make sure any individual or organization has the expertise to care for a special needs child.

Check references, ask if you can contact other special parents who have used the service. Make sure the home or center is clean, well-ventilated and has fire exits, fire drills and other safety features. Find out if the teachers or day care workers are licensed. Note if there is enough staff, enough equipment and toys and if the children look happy and busy. Some large companies have on-site child care or a nearby child care center for their employees. This is the best option of all but is not yet readily available in many workplaces.

Finding the right kind of work. Although we traditionally think of work as 9-5, five days a week, in today's work place there are alternatives better suited to the needs of the single parent.

• *Flexible working hours or "flextime"* is one of these manageable work options. The employee works the same amount of hours but on a different schedule; for example, 7 am-3 pm instead of 9 to 5. Having a job where your hours coincide with your child's school day or day care schedule makes this an attractive choice.

• In *job sharing* two people working different times share one full-time position. For example, one person works only mornings, and the other person takes over the same job in the afternoon. Another arrangement entails working one week on and one week off; there are obviously many other combinations.

• *Part-time work* generally means a few hours each day or a few days per week. While better suited to fulfilling child care obligations, part-time employment, as a rule, offers lower pay and fewer, if any, benefits.

• Your special child's limitations may make *working from your home* a necessity. If you have a marketable skill that you can perform in your own home, this may be an option. You won't have commuting or child care costs; at the same time, however, this type of work requires a great deal of self-discipline and the isolation may trigger feelings of loneliness.

Do's and don'ts

Do find time for yourself. The demands of juggling home, job and parenting tasks can overwhelm and drain even the most organized and competent individual. The best solution is to simplify your household routines as much as possible.

When you do take a break keep things simple—a short walk, a soak in the tub, a good book or TV program may be all that is necessary to refresh yourself and replenish your spirits.

Do remember to have fun with your child. Plan a short outing or excursion that will delight you both.

Do create new family customs, such as pizza every Friday or renting a video on Saturday. By developing your own special traditions you create a rewarding, nurturing environment for the new family unit.

Don't totally rely on your children for emotional support or use them as an excuse not to create a life of your own. This will eventually breed resentment and anger.

Don't hide or isolate yourself because of your changed status. Even if you are not the "joiner" type, finding a group such as Parents Without Partners will help you feel you are not alone.

Do keep your home life as stable as you can by relying on familiar babysitters. This will provide your special child with a sense of security. Remember that handicapped children are more vulnerable than others and cannot protect themselves against the unscrupulous. It's best to make sure you have checked the references of any babysitters who care for your child.

Do set up contingency plans as much as you can. Unforeseen things are bound to occur, so make sure you have alternatives such as substitute babysitters whose references you have checked, etc.

Do be honest. If there are financial worries or you are feeling lonely, ask for help. People aren't mind readers and those in a position to reach out to you may not, simply because they are unaware of your needs.

Don't burden your children with chores or responsibilities that are beyond them emotionally or that overtax their developmental level. This is bound to cause confusion and resentment.

Don't smother your child with lavish affection or gifts because of your own inner guilt feelings. All children, including special children, can detect falseness and insincerity.

Don't continuously focus on the portion of your life that centers around coping with handicaps. Socialize with different people, develop hobbies and other interests. This change of pace will refresh you and give you a sense of renewal so that you can return to your single parent role with vigor.

Do get expert help on taxes and other related issues. Your changed status and child care expenses are reflected in different types of income tax filing. Call the IRS at 1-800-424-3676 for additional information.

Don't neglect your health. Your emotional well being can be compromised by fatigue and illness. You need all your strength to be an effective single parent—that means getting plenty of rest and nourishing food.

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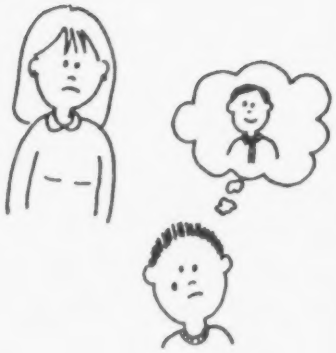
Giving away the newsletter reduces the number of potential subscribers and jeopardizes our ability to keep on bringing *Special Parent/Special Child* to you.

PARENT-FRIEND: ONE TO ONE

A program of parent to parent support

Here is a program from the Easter Seal Society that matches parents and is so valuable it deserves to be duplicated. —The Editors



We recognize your heartache on learning of your child's disability. We serve parents who have children with disabilities or special needs by offering free, individual, one-to-one support and comfort by a parent who has had a similar experience.

Parent-Friend: One to One is based on the philosophy that parents of disabled infants and children are in the process of resolving a most difficult life crisis. One of the most meaningful sources of support is other parents of disabled children who have learned through experience how to cope with similar circumstances.

The purpose of our program is to provide parent-to-parent emotional support, comfort, friendship and reassurance at a time when it is needed most in order to alleviate stress and improve the coping skills of parents who are raising children with impairments, such as those listed here.

When matching possibilities are assigned we also consider the following: traditional nuclear family, adoptive parents, single parent, child in residential/skilled care facility, grief support.

For more information, contact: New York State Easter Seal Society, 845 Central Avenue, Albany, New York 12206 (800-727-8785).

- Accident-related Disabilities
- Achondroplasia
- Anopthalmia
- Anencephaly
- Apnea Monitor Users
- Arnold-Chiari Syndrome
- Arthrogryposis
- Asphyxiating Thoracic Dysplasia
- Asthma/Allergies
- Attention Deficit Disorder
- Addison's Disease
- Bronchopulmonary Dysplasia
- Cancer
- Central Auditory Processing Dysfunction
- Cerebral Palsy
- Child Abuse Related Disabilities
- Cleft Lip/Palate
- Club Foot
- Congenital Adrenal Hyperplasia
- Congenital Cataracts
- Congenital Nevus
- Congenital Structural Malformations
- Congestive Heart Failure
- Cystic Fibrosis
- Cytomegalovirus (CMV)
- Deletion of Long Arm of 18th Chromosome
- Developmental Delay
- Diabetes
- Down's Syndrome
- Dwarfism
- Dyslexia
- Eagle Barrett Syndrome
- Edward's Syndrome
- Emotionally Disturbed
- Encephalopathy
- Epilepsy
- Fragile X
- Gastrointestinal Feeding Requirements
- Genetic Disorder
- Goldenhar's Syndrome
- Growth Deficiency
- Hearing Impairments
- Heart Defects/ Surgeries
- Hip Dysplasia
- Hunter's Syndrome
- Hurler's Syndrome
- Hydrocephaly
- Hyperactivity
- Hypochondroplasia
- Hypotonia
- Ichthyosis
- Incontinence
- Immune Deficiency
- Juene Syndrome
- Juvenile Rheumatoid Arthritis
- Learning Disability
- Mental Retardation
- Multiple Birth Defects
- Muscular Dystrophy
- Myelomeningocele
- Neural Tube Defects
- Neurofibromatosis
- Neuromuscular Disease
- Nutrition Problems
- Oculodentodigital Syndrome
- Osteogenesis Imperfecta
- Ostomy
- Oxygen Requirements
- Paraplegia
- Pertussis
- Pompe Disease
- Prader-Willi Syndrome
- Premature Birth
- Prune-Belly Syndrome
- RH Negative Transfusions
- Rett Syndrome
- Retinitis Pigmentosa
- Rieger's Syndrome
- Schwachman's Syndrome
- Scoliosis
- Seckel's Syndrome
- Seizure Disorder
- Sensory Integration Dysfunction
- Sickle Cell Anemia
- Skin Disorders
- Skin Grafts
- Speech Impairment
- Spina Bifida
- Stickler Syndrome
- Stroke
- Sturge-Weber Syndrome
- T-Cell Deficiency
- Thyroiditis
- Tourette's Syndrome
- Tracheotomy
- Trisomy 18
- Trisomy 13
- Tubes in Ears
- Turner Syndrome
- Visual Impairment
- Werdning-Hoffman Syndrome

PSYCHOLOGIST'S CORNER

Divorce and the parents of a special child

by George Popper, Ph. D.

Even under the best of circumstances, divorce is difficult. Extra complications set in when children are involved and the situation becomes even more devastating when one of those children has special needs.

Anger, frustration and guilt are common feelings for parents when they separate and divorce. Often, parents don't recognize these feelings in themselves or even deny that they exist. Typically, estranged couples will focus their anger on each other; at times, however, the object of this anger may become the special child, whom they unconsciously believe to be the cause of all their problems.

Soon after Joan (real names have not been used) was born it became apparent that she was "different." At first, Joan's mother felt some denial, but after a few years the problem escalated to the point where she refused to bathe, dress, care for her child or have anything to do with her.

David, Joan's father, took on the role of nurturer and became very protective of his daughter. Eventually the marriage ended in divorce and David was given sole custody. After a year of single parenting, he married Beth, who took excellent care of Joan. She wanted a child of her own, however, and two years later gave birth to a son.

David's protectiveness of his daughter increased as Joan grew into young adulthood; unfortunately, so did Beth's anger and resentment! Now Beth has demanded that Joan be placed in a residential facility; if this does not happen soon, she will threaten divorce. David feels trapped between his wife and his child.

This couple is in serious trouble and so are their children. Beth feels her husband has chosen his daughter over her, and claims that David is insensitive to her needs. Other issues are involved, but Joan consistently has been the center of attention. Hopefully, this marriage can be saved even though Beth and David now perceive the situation as hopeless and see no point in trying to change. Both partners must recognize their need to develop a better understanding of their anger and frustration and how to cope with it.

In my work with other families, divorcing parents usually fight to retain custody of their children. The situation is often reversed in the case of the special child—neither parent wants to assume the burden of caring for a child with problems. Although a harsh and perhaps cruel reality, saying it isn't so won't make it better.

The feelings of guilt, frustration, anger, and failure generated by having a special child are natural and need to be addressed before they become a significant problem. When marriages end, it is important to recognize that your special child is not necessarily the source of your problems.

As with any child involved in a divorce, your special youngster's world has been turned upside-down. Remember that a failed marriage can potentially reinforce the feelings of inadequacy so common to special children. Reassure your special child that he or she isn't responsible for the break-up and that both mother and father will always love them.

When a marriage is in trouble, it's best to seek competent, professional help before things get out of hand. Pulling together for the mutual benefit of your children should be your prime concern. More than anything, parents need to set aside the negative feelings they may have for each other so they can continue helping their child grow and flourish.

Illustrations by Leah Spring